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Title

Shared recovery: Couples' experiences after treatment for colorectal cancer

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Abstract

Purpose: Completing cancer treatment involves significant challenges for patients as well as their families. This study aimed to explore couples' experiences of colorectal (bowel) cancer, focusing on the transition after treatment.

Method: Separate, semi-structured interviews were conducted within 12 months of completing treatment with a purposeful sample of ten participants, comprising five patient-partner dyads. Data were analysed using the Framework approach, incorporating dyadic analysis to compare narratives within as well as between couples.

Results: Three main themes were elaborated: the process of recovery, the relationship dynamics, and the mixed experiences of healthcare services. The lasting impact of cancer following completion of treatment was evident for patients as well as their partners, and was shaped by their reciprocal influence on each other.

Conclusions: The findings underscore the value of a systemic approach for supporting couples during recovery from colorectal cancer and demonstrate the need for consistency of healthcare provision across the cancer trajectory, including post-treatment.

Keywords: *colorectal cancer, caregivers, survivorship, qualitative, health care*

Introduction

Completing cancer treatment marks a major transition with new challenges for patients and families (Blum & Sherman, 2010; Mitschke, 2008). Systematic reviews have highlighted the importance of follow-up care and preparing patients for the longer-term impact after treatment (Bennion & Molassiotis, 2012; Lewis *et al*, 2009). Similarly, family caregivers may also need preparation and support to adjust after treatment (Bevans & Stenberg, 2012; Girgis *et al*, 2013; Li *et al*, 2012). Associated difficulties include stress, psychological or physical health problems, sleep disturbances, and financial concerns (Northouse *et al*, 2012). However, there is often a lack of adequate support offered to caregivers (Adams *et al*, 2012; Sinfeld *et al*, 2012) and they tend not to seek support for themselves (Hall *et al* 2012; Mosher *et al*, 2015). This may contribute to the broad range of unmet needs reported by partners and caregivers of adults with cancer (Lambert *et al*, 2012).

In their review of cancer family caregiving, Fletcher *et al*. (2012) outline stress processes affecting family caregivers over the course of the illness. They suggest that further research with caregiver-patient 'dyads' may offer important insights into caregiving. This was echoed by Hagedoorn *et al*. (2011), whose review concluded that further studies are needed "to increase our knowledge of dyadic processes in cancer adaptation". This is of direct clinical relevance given the impact of dyadic processes on patients' and caregivers' physical and mental health (Meyler *et al*, 2007; Walker & Luszcz, 2009). Indeed, the efficacy of psychosocial interventions for cancer caregivers may be influenced by the patient-caregiver relationship (Waldron *et al*, 2012).

The main informal caregiver is often the patient's spouse or partner. For patient-partner dyads (couples), most research to date has explored experiences of breast or prostate cancer (Hopkinson *et al*, 2012). Colorectal (bowel) cancer is the third most common type of cancer within the UK, with increased incidence in recent years (Office for National Statistics, 2012). Treatment and recovery from colorectal cancer can require considerable post-treatment care at home, affecting partners as well as patients (Denlinger & Barsevick, 2009). Qualitative studies have helped to explore various aspects of individuals' experiences of colorectal cancer such as the psychosocial impact and quality of life (Dunn *et al*, 2005; Ramfelt *et al*, 2002; Sahay *et al*, 2001), adjustment to diagnosis and treatment (Hubbard *et al*, 2010; Taylor *et al*, 2001, 2010) including an ostomy or stoma (McMullen *et al*, 2008, 2014), and healthcare needs or preferences (Beaver *et al*, 2010; McCaughan *et al*, 2011, 2012; Rozmovits *et al*, 2004). Some studies have included partners or other relatives, describing issues such as their information needs (Broughton *et al*, 2004), the impact of treatment (Emslie *et al*, 2009;

Ohlsson-Nevo *et al*, 2011, 2012), caregiving and daily life (Houldin, 2007; Sjovall *et al*, 2011), along with the economic and emotional consequences (Céilleachair *et al*, 2012).

The present study focused on couples' adjustment after colorectal cancer and sought to build on the existing evidence-base by focusing on two areas where the need for further research has been identified. Firstly, by adopting a multi-perspective qualitative methodology (Kendall *et al*, 2009), the study aimed to provide a more detailed analysis of patient-caregiver dyads, a gap identified in recent research (Fletcher *et al*, 2012; Hagedoorn *et al*, 2011; Mellon *et al*, 2006, 2007; Waldron *et al*, 2012). Secondly, it included both cancer patients and their caregivers after completion of treatment, a key transition period (Mellon *et al*, 2006; Murray *et al*, 2010).

Methods

Design

Qualitative methodology was adopted to facilitate in-depth exploration of individual experiences (Smith, 2008). Specifically, Framework Analysis (Ritchie & Lewis, 2003) provided a systematic approach that maintained transparency through access to original textual data. As an iterative process, it enabled amendment and additions to the analytic framework throughout, grounding the analysis in participants' accounts. The Framework method allowed for dyadic analysis (Akeson *et al*, 2007; Ellis *et al*, 2012; Singh *et al*, 2010), aided by separate interviews for patients and their partners (Eisikovits & Koren, 2010).

Participants

Participants were purposefully selected for their ability to provide depth and diversity of responses relevant to the study (Tong *et al*, 2007). Patients and their partners were eligible for inclusion if they were an English-speaking adult (over 18 years old) who had completed treatment of curative intent within the past 12 months for their first diagnosis of colorectal cancer. Exclusion criteria were: actively undergoing cancer treatment, confirmed cancer recurrence, or where treatment was known to have failed curative intent. During routine follow-up within one regional colorectal cancer service, the Cancer Nurse Specialist ascertained individuals suitable and interested in participating, who were then provided with further information by the first author. Seven individuals declined to participate (stated reasons were: too busy (n=4), unwell (n=1), hard of hearing (n=1), no longer interested (n=1)). Ten individuals agreed to participate and provided written informed consent. The sample size was comparable to other studies of a similar nature (e.g. Akeson *et al*, 2007; Cup *et al*, 2011), recognising that qualitative methodology can obtain rich information from a small sample or even single case study (Smith, 2008). The fifth couple were purposefully

selected to compare experiences for a younger couple. Sample characteristics and pseudonyms are outlined in Table 1.

Data Generation

Separate interviews gave participants the opportunity to talk about their experiences without the presence of their partner affecting or interrupting their account. This provided a clear distinction of the voices of each individual within the couple, whilst preserving the ability to compare between different couples' narratives (Eisikovits & Koren, 2010). Interviews followed a semi-structured schedule (Table 2), focusing on experiences of services around completion of treatment, and the impact on their relationship. Participants were debriefed after the interview. Interviews were conducted one-to-one with the first author at a hospital clinic (n=6) or participant's home (n=4), according to each participant's preference. Interviews (mean duration of 50 minutes) were audio-recorded, transcribed and anonymised by the first author, who also recorded reflections following each interview.

Data-driven analysis was conducted concurrently with data generation and informed the point at which data were deemed sufficient and recruitment was completed (O'Reilly *et al*, 2013). How data 'saturation' is defined and established remains contentious (Bowen, 2008). Indeed, it has been debated whether it is theoretically possible to achieve true saturation, whether it is practically feasible, and whether it is necessary for the purpose of adequately addressing a research question (Dey, 1999). The study therefore did not seek to achieve 'saturation' in the sense of implied exhaustive completeness, but rather adopted the construct of data 'sufficiency'. Purposeful sampling, data generation and concurrent analysis were continued until enough data had been acquired to provide a rich body of information relevant to the research aims. Sufficiency was deemed to have been achieved at the point where the amount and detail of acquired data enabled elaboration of the thematic framework, with identification of overarching themes recurrent in the additional and final interviews, as well as enough detail to allow discussion of individual differences and nuances within the major themes. The dataset provided evidence for a detailed thematic and dyadic analysis considered to be instructive in relation to the main research aims.

Data Analysis

Analysis of interview transcripts and the first author's reflections adhered to the five step process of Framework Analysis (Ritchie & Lewis, 2003). This involved: becoming familiar with the data through transcribing, repeatedly reading and reflecting on the data; developing an initial thematic framework based on key concepts from participants' accounts, which was used to begin organising and classifying the data; identifying and indexing portions of data

relating to specific themes, represented as codes; reorganising data into charts of the themes, using headings to compare across the whole dataset whilst keeping reference to the original context as shown in Table 3; searching for patterns and explanations and using diagrams to develop interpretations. Figure 1 (based on Fletcher *et al.*'s 2012 model) illustrates a diagrammatic representation showing the patient-partner relationship dynamics set in context alongside the interaction with the healthcare system, with the recovery process illustrated by the underlying trajectory arrow. Appendices which further demonstrate the earlier stages of framework analysis including the developing framework and indexing with transcript sample can be provided by the first author on request.

In addition to analysis of individual interviews, dyadic analysis compared overlaps and contrasts within and between couples (Eisikovits & Koren, 2010). This highlighted differences in couples' relational styles as well as individual differences for the sample of patients compared with partners.

Rigour

The study received ethical approval from the West of Scotland Research Ethics Service. In line with recommended criteria for ensuring rigour in qualitative research (Braun & Clarke, 2006; Tong *et al.*, 2007), strategies were adopted to improve the trustworthiness of the findings which included the following steps. A consultation group of four patients and one partner-caregiver provided input on development of the study, including the participant information sheets and consent forms, the interview schedule, and the analytic framework. This was conducted in line with recommendations on service user involvement (Trivedi & Wykes, 2002). Participants were invited to give feedback or 'member reflections' (Tracy, 2010) on a written summary of the findings. In addition, the co-author and consultation group provided alternative viewpoints to the first author's perspective during data analysis. By addressing both overlap and contrast in the narratives, the dyadic analysis actively sought differing views, facilitating negative case analysis.

Findings

Three overarching themes were identified: recovery, relationship dynamics, and healthcare services. Within each of these themes, dyadic analysis elaborated areas of *overlap* within and between couples, contrast *between* couples, and contrast *within* couples.

Recovery: '*pick yourself up and get on as best you can*'

There were commonalities or 'overlap' within and between couples' narratives of recovery

following treatment for colorectal cancer. Recovery was seen to be shaped by the extent to which cancer affected their lives physically, emotionally and more broadly, and by people's responses or coping styles. In particular, 'stoicism' was recurrent in every interview, prevalent in both patients' and partners' narratives. Examples were found of three aspects of stoicism described by Wagstaff and Rowledge (1995), namely: emotional non-involvement, lack of free expression of emotions, and exercise of emotional control to withstand difficulties.

"Everybody keeps saying, 'Did you have a good cry about it?' and I haven't. Not yet. And I don't think now I ever will." (Dawn, patient)

"I suppose it was an unsaid thing. ...Me, I didn't mention it, just sort of kept it to myself." (David, partner)

"Life's not always plain sailing. And things do go wrong, you know. And you've to pick yourself up and get on as best you can." (Beth, patient)

Related to this third aspect, some participants perceived stoicism as a helpful source of strength or way of coping with adversity, and even attached a sense of identity to it. However, sometimes stoicism resulted in unshared feelings and concerns, or formed a barrier to accessing support, as described by David.

"There've been days she [the patient] was pretty unhappy about her situation... Maybe she should have phoned the nurse more than she did to see what was available but again, I suppose, we are folk that dinna [don't] ask for help... what she feels-, or, well, felt, deep inside, I'll probably never know. Em, she probably kept some of that to herself all the way through this. Put a brave face on it... She didn't know what was available or what else was on the go. And being her, she wouldn't ask either." (David, partner)

The analysis also highlighted areas of contrast between couples. Four participants reported a relatively straight-forward recovery journey, whereas the others described various complications impeding their progress. Three of the couples described side-effects having a lasting impact on the patient's mood and irritability after completion of treatment. This was contrasted by another couple, Arthur and Agnes, who both viewed recovery as "plain sailing".

"I do snap at him sometimes - I still lose my temper sometimes." (Beth, patient)

"She started to get a bit of a temper. You know, it was frustration more than anything else." (Bruce, partner)

"I dinnae [don't] think I felt frustrated, like. I dinnae think I felt that since day one." (Arthur, patient)

"He's a placid kind of laddie, he doesnae- [doesn't], he never gets bad tempered or nothing" (Agnes, partner)

Irritability, frustration and low mood were compounded if the patient's expectations of a timely recovery were not met, as illustrated by Colin's description of his experience after treatment. Similarly, his partner spoke of the initial post-treatment period as a challenging time, navigating the tension between trying to help while needing to allow the patient space to recover.

"I just thought, 'It was an operation, give me a couple of weeks and I'll be up and about'. But that was nae [not] the case... [Recovery] was very, very slow. In fact I thought it wasnae [wasn't] even moving. I was just sort of stuck... I realise that now, that I was actually getting better but it was so slow that I couldnae [couldn't] see it within myself." (Colin, patient)

"He struggled quite a bit. And he just wanted to be sort of on his own often, just shut away, and: 'Dinna bother wi' [with] me... Just shut the bedroom door, I want to sleep...' So, it was quite hard going that time. Because, maybe we're over-protective, I dinna know, but, eh, ken [you know], you're aye [always] wanting to help. But sometimes you have to step back a wee bit and let them get through things themselves" (Claire, partner)

The broader impact on their lives also varied. For some participants, there were considerable and lasting consequences for their work, social or home life, whereas others emphasised how little disruption they had faced. The wider life context appeared to be an important factor, with a more complicated recovery for those facing concurrent stressors such as financial concerns or other health problems.

Contrast within couples was also evident. For instance, Beth said she was now *"quite optimistic"* about the future, whereas her husband described feeling *"just, apprehensive... that something could go wrong now."* Patients and partners were not necessarily aware of what each other found most difficult. Evan said that he had found the on-going financial worry was the most challenging part and said that he thought this was also the case for his partner. However, she said the hardest part was the initial period of *"not knowing and waiting"* and assumed this was also true for Evan.

Relationship dynamics: 'what I'm going through, she goes through as well'

In every interview, there was a theme of cancer as a shared experience, even in relation to the patient's physical symptoms or medical care.

"We had a lot of accidents wi' my stoma" (Colin, patient)

"Hopefully we'll get this reversal and get nearer back to normal." (Claire, partner)

Partners closely identified with the patient's experience and, similarly, that patients thought of cancer as something they were facing together. Despite the challenges for their relationship, several participants said that cancer ultimately had little or no impact on their relationship, or even a positive impact.

"...when you argue wi' somebody and fall out and that, it's so easy to walk away. But when you've been through something like this, it makes you realise just how important that person- it's made a big difference, for me, for our relationship." (Emma, partner)

However, the perception of being involved in the cancer experience could be complicated for partners by a concurrent sense of being helpless and restricted to being an onlooker, as David illustrated.

"...obviously I was caught up in it. But I was, like, a, just a bystander. I couldn't help in any practical way." (David, partner)

Some of the patients acknowledged their partner's sense of helplessness but described how their partner was actually a "rock" for them, a vital source of support and stability. As Colin expressed, *"I doubt I maybe could have survived if I'd just been on my own."* In turn, partners emphasised how mutual support had helped them to cope.

An area of contrast between couples was communication and the extent to which thoughts and feelings were shared. For one couple, it was the partner who prompted the patient to seek medical advice whereas another partner said she initially chose not to share her concerns about the possibility of a cancer diagnosis with the patient to spare him concern. Some things were not openly discussed simply because the person assumed they knew what the other thought or wanted. In other instances, participants said that they deliberately left things unspoken in an attempt to avoid upsetting the other. Both patients and partners alike described trying to protect each other in this way.

"I probably didn't say as much as I should have, just to sort of protect him a little bit." (Beth, patient)

"I would try to be careful nae [not] to saying anything that would upset her too much." (David, partner)

Differing relational styles were also apparent. For instance, Beth specified that preserving a degree of mutual independence was important to the successful functioning of their relationship, whereas Colin and Claire appeared to prefer a more mutually-dependent lifestyle.

"You've your own interests and your own friends, you know. Whereas if you're just a couple, and you don't do anything apart from each other, you're lost."
(Beth, patient)

"We're quite happy 'cause we do everything together and, eh, no, things work. Because if I go out walking, she comes wi' me, and if we're going anywhere at weekends or anywhere we go – we never go on holiday separately, we always go together." (Colin, patient)

Within couples, there were some contrasting perceptions of each other's experiences. The belief that the cancer experience had been more difficult for the other person was expressed by both patient and partner.

"I think my husband was actually more bothered by it than I was"
(Dawn, patient)

"Once you've gone through that, it's got to leave an impression. Not so much for me but more for [Dawn]."
(David, partner)

Healthcare Services: 'leaving you to get on with it'

There was little overlap between couples in their reported experiences and opinions of healthcare services. Participants shared the view that adequate information and availability of healthcare professionals were important, but differed on whether or not they had received these themselves. When asked, the reply from every participant was that there had not been any offer or suggestion of support specifically for the partner. While all the partners in the sample accompanied the patient to hospital, not all were aware they could attend appointments jointly.

There was notable contrast between different couples' reported experiences of healthcare services, but within each of the couples interviewed, there was a high degree of overlap in the opinions of healthcare shared between patients and their partners. Where the patient perceived good availability of support, this was echoed in the narrative of their partner.

"If there was anything outwith, I've got numbers to just give them a ring. So I've found it excellent. ...the back-up and everything was there." (Colin, patient)

"We've had brilliant- all the way through...We could have phoned any of them at any time, uh huh, which was good." (Claire, partner)

Similarly, where the patient expressed dissatisfaction or disappointment with an aspect of their healthcare, this too was evident in their partner's account.

"Quite a lot of them are not very good at telling you what, what's going on." (Dawn, patient)

"They're not giving you a lot of information." (David, partner)

Couples held differing preferences for follow-up care. Beth and Bruce commented on their relief that she was not required to go for a more frequent scan, since they both perceived this as indication of a better prognosis. Conversely, Agnes and Arthur indicated that they would have preferred to have a scan sooner and that waiting for results was an anxious and difficult time. Emma also said that her preference would have been for Evan to receive more regular scans and attributed the delay to services trying to save money.

Some participants spoke with high regard for the healthcare they had received. They commended the personable staff who took time to explain or discuss issues and showed personal interest by talking more informally. However, others described negative experiences, such as not feeling well-informed while left waiting for treatment or results. Some participants commented that staff lacked the time or resources to provide support, or that it was unclear what support was available.

"I know that in here, a week in here is just- it, it doesnae mean nothing because it's just, they're so busy, so busy and things like that, but it-. But a week to me would seem to be a lifetime really because I was thinking, 'What's happening? What's happening?'" (Colin, patient)

A lack of further information or follow-up contributed to feeling "left" or "deserted" after treatment completion, as described by three of the patients and one partner.

"[There was] nothing helpful in the sense, eh, well as far as I know, eh, sort of like, 'Have you seen about this, have you seen about that, did you know that this was available?' that kind of thing. I don't know of anything like that. I thought it was, em, how to say? Kind of leaving you to get on with it." (David, partner)

Despite the high concordance between patients' and their partners' perceptions of healthcare services, some contrasting views were evident within couples. Beth and Bruce described services as a highly efficient system. However, for Beth, this actually contributed to the feeling of anonymity and abandonment.

"You're booked in and it's just a seamless operation... you sort of find you're in the system and you're just a number ...you're just passing through the system, you know. It's just so organised ... you've all this attention and then suddenly it all disappears. You know, you're left to get on with it. ...you feel a bit let down I think. You think, 'Okay, they've done all this, but they don't really want to know any more about you' ... I feel deserted, really." (Beth, patient)

By contrast, her husband perceived the efficiency as wholly positive.

"...when we come back, 'We've made an appointment for you at the hospital.' Just done like that. Found they were very efficient that way. ...I couldn't fault them." (Bruce, partner)

There were also differences in how patients and partners obtained and understood information. For instance, Dawn described having received test results by telephone prior to her follow-up appointment but it would appear that this information was not shared with her partner, who described the tension he felt waiting to be called in to that appointment to get the results. Similarly, it appeared that Colin knew the planned ending for contact with a community nurse, whereas his wife did not. Even where information was given to both, it could be understood differently by the patient and partner, as Evan illustrated when describing the appointment to get results after treatment:

"Never exactly said that you were clear. Eh, you know, Emma says: 'You got the all clear,' but [the doctor] never exactly said that." (Evan, patient)

Discussion

The findings lend support to the conceptualisation of cancer treatment completion as a major transition point with challenges and uncertainties for both patients and partners (Blum & Sherman, 2010). Despite these difficulties, people do not necessarily access relevant support (c.f. Bevans *et al*, 2011; Harrison *et al*, 2012). In some instances, this was because participants were unaware of the potential support available, underscoring the importance of providing sign-posting and addressing informational needs (Given *et al*, 2012). In other cases, accessing support appeared to be affected by a stoical coping style.

Stoicism was described by participants as a natural or necessary response to challenging circumstances. Stoicism was perceived positively, though it was also acknowledged that stoicism could inhibit expression of feelings and prevent help-seeking. Knott *et al.* (2012) reported that patients reverted to showing a 'brave face' only after failed attempts to elicit help from others and argued that excessive emphasis on maintaining positivity or a 'fighting spirit' can inadvertently increase patient burden. The current study indicates that social and healthcare support networks but also patients could benefit from awareness of this risk. Underlying a stoical presentation, people may have significant difficulties that could be alleviated by information or support. Therefore, healthcare services may need to adopt a proactive approach (Hall *et al.*, 2012), with sensitivity to individual and cultural differences. Where there are unshared concerns, a balance is needed to encourage accessing relevant help without undermining a person's coping style or sense of autonomy.

Coping styles, appraisals and adjustment are conceptualised as 'dyadic' by Berg and Upchurch's (2007) model of couples facing chronic illness. They note the varied extent to which patients and partners perceive joint 'ownership' of the illness experience. In the current study, this was reflected in participants' language regarding cancer as a shared experience. In-keeping with prior research (Morgan *et al.*, 2011; Segrin *et al.*, 2012), patients in this study described their partners as a vital source of support and said that their own well-being and recovery was influenced by how their partner responded. Some participants echoed previous findings that the cancer experience ultimately strengthened their relationship (Dorval *et al.*, 2005; Ka'Opua *et al.*, 2007; Tanner *et al.*, 2011). Dyadic analysis also showed the potential for miscommunication and misunderstandings between patients and partners. Unshared concerns and lasting mood changes, such as increased irritability, can put additional pressure on relationships. In addition, some participants placed a high value on independence within their relationship. Healthcare professionals should therefore be alert to potential difficulties when physical impairment and reduced functioning necessitate greater dependence for the patient. This can prevent patients and partners from having adequate time and space to themselves which can be particularly problematic for some couples. Awareness and assessment of this could help identify couples who may benefit from additional support such as respite care (Harding & Higginson, 2003).

By comparing overlap and contrast *within* and *between* couples, the findings highlight the importance of person-centred care to accommodate different preferences for information, family involvement or frequency of follow-up. Although some couples reported good support from healthcare services throughout their journey, others appeared to feel let down and deserted following treatment completion. This may reflect a number of factors including:

disparity of access to services, differences in uptake of what is available, and differences in specific needs, expectations and attitudes to help-seeking (Steginga *et al*, 2008; Szczepure *et al*, 2008). The perceived availability of support can be important in itself. Even when couples do not need or choose to contact staff after completing treatment, they may be reassured by knowing whom to contact if necessary. Some participants noted the value of timely telephone contact lasting just a few minutes. Brief reassurance, normalising, or directing towards relevant resources may be sufficient and significant during recovery (Williamson *et al*, 2014).

By analysing contrast within couples' narratives, some disparity was apparent in their beliefs and feelings about the patient's prognosis. Post-treatment fear of recurrence is well-recognised in patients (Simard *et al*, 2010) but can also prove a significant difficulty for partners (Mellon *et al*, 2007), even when the patient has an optimistic outlook, as this study affirms. Recognising this, there has been suggestion of routinely involving caregivers in survivorship care planning (Given *et al*, 2011). The present study demonstrated some of the complexities around caregivers' attendance or involvement in follow-up care. For example, a patient and partner could come away from the same appointment with different understandings, and couples can have differing expectations of follow-up care. These findings reaffirm the importance of communication in healthcare (Fallowfield & Jenkins, 1999), which was a recurrent issue in the participants' reported experience of services. Explaining the rationale for the length of time between scans could alleviate concerns and improve satisfaction with services. Evidently, information given to the patient is not necessarily shared with their partner. With patient consent, healthcare services should keep caregivers informed when appropriate and provide them with opportunities to ask questions about treatment or follow-up. There is clear value in taking time to ensure both patients and their relatives understand the information they have been given, have had their questions addressed, and feel recognised as individuals. However, challenges remain in ensuring this is done in practice. Participants in this study described healthcare teams as highly busy and under-staffed. Priorities for allocation of limited resources should include protecting staff time for these valuable discussions and providing relevant training and support in this role.

The findings reaffirm the value of being informed and prepared for the longer-term impact after treatment (Bennion & Molassiotis, 2012; Kidd, 2014) and the importance of follow-up care (Lewis *et al*, 2009). Disparity between couples' experiences of treatment and follow-up was apparent, indicating that family support has yet to be adopted systematically rather than on an ad hoc basis (Turner *et al*, 2007). The study illustrated how ongoing availability of healthcare support and timely reassurance or advice could alleviate distress. The uncertainty and difficulties that resulted when participants experienced a lack of support were also noted.

These findings reinforce existing evidence of the adverse impact of poor communication and, conversely, the benefit of quality psychosocial care for alleviating distress and improving quality of life (Chochinov *et al*, 2013; Street *et al*, 2009). It was not possible from this study to elaborate more fully why different couples had differing experiences of family support from healthcare services. Further research may help explore why some couples appear to navigate their way through services more successfully than others – to what extent this may be due to individual characteristics of the patients and their partners and to what extent this may be affected by different constraints on staff time or other factors. The findings do suggest a need for more consistent signposting to ensure patients and their partners or relatives are aware of, and have access to, the support available.

Limitations

As a small, exploratory study, the sample and data generation were necessarily limited in scope. In order to participate in the study, both members of the couple had to consent, which could have biased the sample towards more cohesive couples. Furthermore, the Cancer Nurse Specialist's initial involvement in purposeful selection of participants could have affected the recruitment of individuals who were lost to routine follow-up or who had a conflicted relationship with healthcare services. A number of potential participants declined to take part in the study. Those who agreed to participate may represent a group that were comparatively well and had enough free time and these sample characteristics may have affected the experiences or issues raised.

Future Research

With sufficient resources, future research could purposefully sample a larger or more diverse sample, for instance with other types of caregivers and with other types and stages of cancer, include second interviews with participants separately or jointly as a couple, and adopt other methods for obtaining member reflections. Further analysis of interpersonal dynamics could be enabled by purposefully recruiting couples with relationship difficulties, who may typically be under-represented in this type of research. It would also be informative to explore dynamics between couples and the healthcare team by including relevant healthcare professionals within multi-perspective analysis (Yosha *et al*, 2011). Ways of facilitating good communication within couples and with the healthcare team could be fruitful avenues for future research (Moore *et al*, 2009). Further exploration of the cultural influences on coping styles such as stoicism, and its influence on communication and on help-seeking behaviour, may shed light on barriers to accessing services (Anderson *et al*, 2002; Steginga *et al*, 2008).

Conclusions

The physical, emotional and broader impact of cancer can endure beyond the completion of treatment, particularly for those who encounter medical complications or other concurrent difficulties. Patients and partners can have a significant impact on each other through their experiences and responses during this recovery process. Their awareness of this reciprocal influence may contribute to efforts to appear stoical, partly to avoid causing each other concern, which can result in unshared difficulties or concerns. Healthcare professionals have a role in facilitating good communication and ensuring adequate support is made available to couples and families as a whole.

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Table 1. Sample characteristics

Pseudonym	Gender	Age	Ethnic origin	Employment status	Treatment type	Months post-treatment	Marital status	Duration of relationship
Arthur (patient)	M	69	White, British	Retired	Surgery and Chemotherapy	4	Cohabiting	15 years
Agnes (partner)	F	73	White, British	Retired				
Beth (patient)	F	72	White, British	Retired	Surgery and Chemotherapy	3	Married	51 years
Bruce (partner)	M	72	White, British	Retired				
Colin (patient)	M	67	White, British	Retired	Surgery, Radio- & Chemotherapy	2.5	Married	45 years
Claire (partner)	F	67	White, British	Retired				
Dawn (patient)	F	63	White, British	Retired	Surgery and Chemotherapy	2	Married	46 years
David (partner)	M	64	White, British	Employed				
Evan (patient)	M	40	White, British	Self-employed	Surgery and Chemotherapy	2	Cohabiting	5 years
Emma (partner)	F	33	White, British	Employed				

Table 2. Semi-structured interview schedule

-
- *Can you tell me about your experience of [// your partner] having had cancer?*
 - *Before finally completing treatment, what advice or support, if any, did you receive to help prepare for the end of treatment and the period afterwards?*
 - *Can you tell me about your experiences since finishing treatment?*
 - *Have you had any contact with services since finishing treatment? (If yes, What was that like?)*
 - *Overall, have your experiences had any impact on your relationship as a couple?*
 - *Since the diagnosis, has your partner come with you [// have you gone] to any appointments or spoken with any staff? (If yes, What was that like?)*
 - *Was there any support offered to your partner [// to you, as a partner]?*
 - *Was your partner [// Were you] involved in your [// your partner's] care in any way?*
 - *Do you think that the way your partner responded to situations made a difference to you? (If yes, In what way?)*
 - *Thinking about your experiences of healthcare services, was there anything you found helpful or positive?*
 - *From your experiences of services, was there anything unhelpful or not positive?*
 - *Is there something [else] you think services could do to help couples or families adjust after treatment?*
-

Prompts for further information were given as appropriate; closed brackets indicate amendments for interviews with partners.

Table 3. Framework analysis stage 4: Charting of key themes for dyadic analysis across dataset

	Arthur	Agnes	Beth	Bruce	Colin	Claire	Dawn	David	Evan	Emma
Recovery: factors facilitating or disrupting recovery from cancer										
Medical Complications			✓		✓		✓	✓		
No Medical Complications (Straight-forward)	✓	✓							✓	✓
Patient Low in Mood			✓			✓		✓		✓
Patient More Irritable			✓	✓	✓	✓			✓	✓
Life Context / Other Stressors			✓	✓	✓	✓	✓	✓	✓	
Recovery process	✓	✓	✓✓	✓✓	✓✓	✓	✓	✓	✓	✓
Stoicism	✓✓	✓✓	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓	✓✓
Hope	✓	✓	✓	✓	✓	✓		✓	✓	
Support from Healthcare System	✓		✓	✓	✓✓	✓✓			✓	✓
Support from Wider Network	✓	✓	✓✓	✓✓		✓	✓		✓	✓
Relationship: dynamics between the Patient and Partner										
Overlapping comment	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Contrasting comment			✓	✓	✓	✓	✓	✓	✓	✓
'We' experienced it Together	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Little or No Impact on Relationship	✓		✓	✓	✓		✓	✓		
Positive Impact on Relationship					✓	✓			✓	✓
Challenges for Relationship			✓	✓	✓	✓	✓	✓	✓	✓
Issues Left 'Unspoken'			✓	✓		✓	✓	✓✓	✓	✓
Needing Space		✓		✓	✓	✓	✓			
Perceived Experience as Worse for the Other				✓	✓		✓	✓		✓
Services: Experiences and Opinions of Healthcare Services										
Positive Experiences of Healthcare	✓	✓	✓✓	✓	✓✓	✓✓	✓	✓		✓
Negative Experiences of Healthcare			✓	✓	✓	✓	✓✓	✓	✓	✓
Communication Difficulties with Healthcare Team	✓	✓	✓	✓	✓	✓	✓	✓✓	✓	✓
Waiting	✓	✓	✓	✓	✓	✓		✓	✓	✓
Left by Services			✓		✓		✓	✓		

✓ denotes instances of theme found in indexing of transcript ✓✓ denotes theme highly prevalent as indicated by 10+ instances within transcript

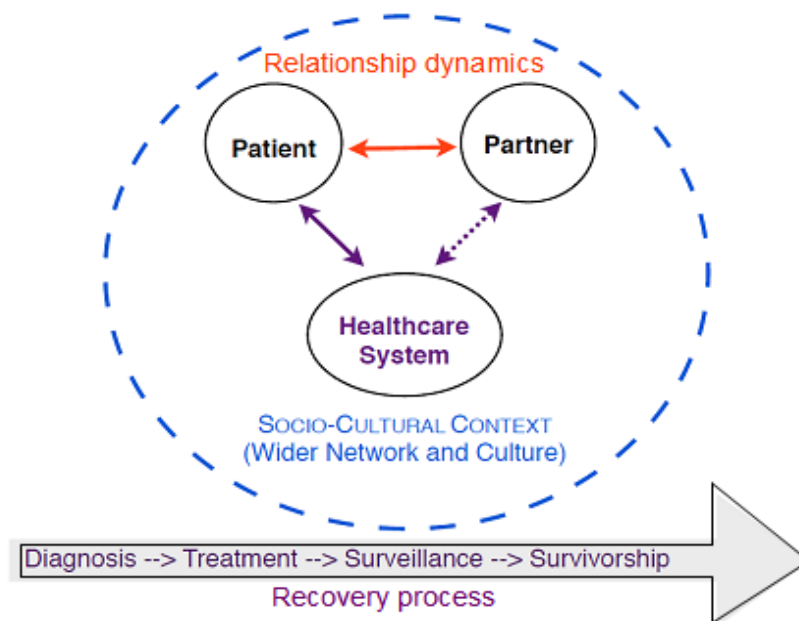


Figure 1. Framework analysis stage 5: Diagrammatic representation of analytic framework